# California HIV/AIDS Update



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### Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers — Maryland and Texas, 1994-1996

(reprinted from *Morbidity and Mortality Weekly Report* 1998;46:1254-1258, 1271)

Notifiable disease reporting laws or regulations in states and territories require reporting of acquired immunodeficiency syndrome (AIDS) cases, including patient and physician names, to state or local health authorities. As of January 1, 1998, a total of 31 states were conducting namebased human immunodeficiency virus (HIV) case surveillance by using the same methods as surveillance for AIDS. However. because of concerns about namebased HIV surveil-lance. Maryland and Texas imple-mented HIV surveillance using non-name unique identifiers (UI)\*. report summarizes a 3-year collaboration by CDC and these states to evaluate UI surveillance for HIV infection; the findings indicate some limitations to the use of a Social Security numberbased UI for HIV surveillance.

In both Maryland and Texas, UI surveillance for HIV was imple-mented in early 1994, and both used the same 12-digit numeric UI code (comprising the last four digits of the patient's Social Security number [SSN], six-digit [month/day/year] date of birth [DOB], one-digit code for race/ethnicity, and one-digit code for sex). HIV-infection reports included residence diagnosing facility, and date of test, but did not include mode of HIV exposure. In both states, UI HIV surveillance databases were maintained sepa-rately name-based AIDS surveillance databases.

Evaluation criteria included the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases.

Reporting in Maryland is exempted for nonstate residents; persons who are tested at anonymous test sites; are blood, semen, or tissue donors, and participants of certain research projects. No exemptions to reporting exist in Texas.

In Texas, selected HIV reports also were evaluated for ability to follow back UI reports to patient records; in Maryland, provider compliance with maintaining patient surveillance logs was assessed. During July 1994-December 1996, Maryland reported 6412 AIDS cases and received 9971 HIV-infection reports, and Texas reported 12,041 AIDS cases and received approximately 23,000 HIV-infection reports.

#### Maryland

In 1993, the Maryland legislature mandated UI reporting of both positive HIV tests and patients with CD4+ T-lymphocyte counts < 200 cells/ $\mu$ L (CD4+) $^{\dagger}$ . Health-care providers requesting HIV or CD4+ tests are required to construct the UI code for each patient, include the code on the laboratory slip, and record it in a surveillance log that matches the UI to patient identifiers (e.g., medical record number, patient name, or other patient code) for purposes of case investigation and follow up. Laboratories licensed by Maryland are required to submit the UI-based reports to the state health department through the local heath departments.

Of 9971 HIV-infection reports entered during

TABLE 1. Number of reports of HIV infection and percentage of reports that included data elements for unique identifiers (UIs), by reporting period—Maryland (MD) and Texas (TX), July 1994-December 1996

| Reports/Data<br>element   | State  | July-<br>Dec. 1994 | Jan<br>June 1995 | July-<br>Dec. 1995 | Jan<br>June 1996 | July-<br>Dec. 1996 | Overall |
|---------------------------|--------|--------------------|------------------|--------------------|------------------|--------------------|---------|
| Total no. reports         | MD     | 2,238              | 1,691            | 1,866              | 1,881            | 2,295              | 9,971   |
|                           | $TX^*$ | 3,932              | 3,399            | 3,597              | 2,852            | 2,339              | 16,119  |
| Data element <sup>†</sup> |        |                    |                  |                    |                  |                    |         |
| Social Security           | MD     | 69.6               | 73.1             | 81.2               | 83.5             | 84.5               | 78.4    |
| number                    | TX     | 56.7               | 68.6             | 65.0               | 69.5             | 75.2               | 66.0    |
| Date of birth             | MD     | 95.2               | 96.3             | 98.7               | 99.3             | 98.8               | 97.6    |
|                           | TX     | 88.4               | 89.8             | 93.1               | 96.8             | 97.6               | 92.6    |
| Sex                       | MD     | 96.8               | 97.2             | 98.7               | 99.2             | 99.4               | 98.3    |
|                           | TX     | 91.5               | 97.5             | 98.4               | 99.1             | 97.9               | 96.6    |
| Race/Ethnicity            | MD     | 85.8               | 88.5             | 91.6               | 94.0             | 89.9               | 89.8    |
| J                         | TX     | 80.8               | 91.6             | 94.4               | 97.1             | 95.4               | 91.1    |
| % Reports with            | MD     | 61.3               | 65.9             | 74.9               | 78.5             | 76.5               | 71.4    |
| full UI                   | TX     | 51.8               | 61.9             | 61.6               | 66.5             | 71.3               | 61.6    |

<sup>\*</sup>Excludes approximately 7000 records that had three or more missing UI data elements.

July 1994-December 1996, all UI elements were present for 7119 (71%) (Table 1). Element-specific presence ranged from 78% (SSN) to 98% (DOB and sex). The proportion of reports with full UI increased during July 1994-June 1996, and declined slightly during July-December 1996. The median time from date of HIV test to receipt of report by the state health department was 20 days (range: 1-847 days). During October-November 1997, all 72 providers in nine counties of eastern Maryland (the counties reported 3% of AIDS cases in Maryland in 1996) for whom laboratories had submitted HIVinfection reports were contacted to determine the proportion of providers who maintain the required surveillance log linking UI to patient identifiers; 32 (44%) of these providers maintained logs.

Completeness of HIV-infection reporting was estimated by comparison to cases of AIDS reported in the AIDS surveillance registry. Of AIDS cases with dates of HIV diagnosis from July 1995 through June 1996, data elements to construct UI were available for 633 (85%) cases. Of these, 319 (50%) matched to HIV-infection reports with full UI in the UI database (Table 2).

Data from the Maryland HIV counseling and testing (C&T) system (excluding sites offering only anonymous HIV tests) were used to evaluate the proportion of records with full UI and completeness of HIV-infection reporting. In early 1995, counselors were instructed to obtain UI code information from

clients and record the UI on the HIV C&T record. During 1995-1996, a total of 1093 records with a positive HIV test were entered into the C&T database; of these, all UI elements were present for 94%. HIV C&T reports for persons who had HIV diagnosed from July 1995 through June 1996 were matched to the UI database. Of the 528 reports, 276 (52%) matched.

 $<sup>^{\</sup>dagger}HIV\text{-}infected$  persons with a CD4+ T-lymphocyte count of <200 cells/ $\mu L$  meet the 1993 expanded AIDS surveillance case definition and are reportable by name for AIDS surveillance.

<sup>&</sup>lt;sup>†</sup>Proportion of all reports containing specific UI data elements.

TABLE 2. Percentage completeness of HIV-infection reporting, availability of unique identifier (UI) data elements in alternate databases, and sources of report—Maryland and Texas, July 1994-December 1996

| Characteristic                   | Maryland<br>(n= 9,971) | Texas<br>(n=16,119)              |
|----------------------------------|------------------------|----------------------------------|
| Completeness of reporting        |                        |                                  |
| $HIV^*$                          | 50.4                   | 26.0                             |
| CD4+ T-lymphocyte count*         | 44.4                   | $\mathbf{N}\mathbf{A}^{\dagger}$ |
| HIV§                             | 52.3                   | NA                               |
| Availability of UI data          |                        |                                  |
| elements in alternate            |                        |                                  |
| databases                        |                        |                                  |
| Birth <sup>1</sup>               | No                     | No                               |
| Death                            | Yes                    | Yes                              |
| Sexually transmitted             |                        |                                  |
| disease                          | No                     | No                               |
| Tuberculosis                     | No                     | No                               |
| Drug assistance**                | Yes                    | Yes                              |
| Medical assistance <sup>††</sup> | Yes                    | No                               |
| Hospital discharge               | No                     | No                               |
| Source of HIV report             |                        |                                  |
| Public                           | $30\%^{\S\S}$          | $77\%^{\S\S}$                    |
| Private                          | 70%¶                   | $23\%^{***}$                     |

AIDS cases reported through July 1997 compared with the UI database. Not available.

#### **Texas**

In 1994, the Texas Board of Health amended regulations to require named reporting of HIV-infected children aged < 13 years and UI reporting of HIV-infected adolescents and adults. Both health-care providers ordering an HIV test and laboratories performing the test report confirmed HIV infections to the Texas Department of Health (TDH) through the local health departments. Neither providers nor laboratories are required to maintain registries linking UI to patient identifiers.

Approximately 23,000 HIV-infection reports were received at TDH during the evaluation period. Since 1995, TDH excluded approximately 7000 paper HIV reports with three or more missing UI data elements. Of 16,119 HIV-infection reports entered

into the UI database, all UI elements were present for 9923 (62%) (Table 1). Element-specific presence ranged from 66% (SSN) to 97% (sex). Overall, 60% of reports were submitted in periodic batches, which had a longer time from date of HIV test to receipt by TDH (median: 173 days; range: 26-974 days) than the 40% of reports submitted individually (median: 59 days; range: 2-906 days).

Completeness of HIV-infection reporting was estimated by comparison to AIDS surveillance data using the same methodology as in Maryland. Data elements to construct UI were available for 1762 (79%) of AIDS cases with dates of HIV diagnosis in the specified period (Table 2). Of these, 454 (26%) matched to HIV-infection reports with full UI in the UI database.

To evaluate the feasibility of epidemiologic follow up, TDH sampled 765 HIV-infection reports submitted during January 1995-June 1996, in six areas of the state, reflective of variation in geography, demography, HIV morbidity, and reporting sources. Of these, 456 (60%) could be matched to a client record using any combination of UI (including records without full UI), health-care provider name, date of test, residential information, and other locally available information. Matched records that were missing the SSN data elements (n= 208) were reviewed to determine whether these data could be located. SSN could not be located for 120 (58%) of these records.

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#### **Editorial Note**

HIV and AIDS surveillance data are needed to provide reliable population-based data to guide public health programs. During 1995-1996, the first declines in the incidence of AIDS-opportunistic infections and AIDS deaths were reported in the United States (6% and 23%, respectively), in part, as a result of increasingly effective HIV therapy (1). On the basis of revised HIV treatment guidelines (2), the impact of treatment advances on AIDS trends is expected to continue and will reduce the usefulness of AIDS data alone to monitor HIV-infection trends and morbidity. CDC and other public health and advocacy organizations have recognized the need for national HIV case surveillance while continuing to discuss the relative merits of HIV surveillance

<sup>§</sup>HIV cases diagnosed from July 1995 through June 1996 in HIV counseling and testing sites compared with the UI database.

<sup>&</sup>lt;sup>1</sup>Used for pediatric AIDS surveillance only.

<sup>\*\*</sup>Federal- and state-funded medication program.

<sup>††</sup>Federal- and state-funded medical assistance program.

<sup>§§</sup>Includes local health departments and state laboratory.

<sup>&</sup>lt;sup>¶</sup>Includes community-based organizations and private clinics and laboratories.

<sup>&</sup>quot;Includes community-based organizations, hospitals, private physicians, clinics, and laboratories.

methods based on numeric codes compared to the name-based approach employed for AIDS surveillance (1,3).

CDC uses established criteria to evaluate performance of public health surveillance systems to provide accurate data to target prevention and care programs (4). States conduct active surveillance using existing name-based clinical and public health records to decrease the reporting burden on providers, eliminate duplicate reports, and facilitate epidemiologic follow-up. These methods enable AIDS surveillance to attain high performance standards as reflected by completeness of reporting (> 85%) (5) and documentation of risk exposures ( $\geq$  93% of cases) (6). Evaluation of name-based HIV surveillance has shown 74%-97% completeness of reporting (7; CDC, unpublished data, 1997), and documentation of risk exposures (> 76% of cases) (6). Secure and confidential surveillance practices are required as a condition for receipt of federal resources for HIV and AIDS surveillance. At the state level, the most comprehensive protections of medical data apply to government-held data, and most specifically to HIV-related data (8). Names are removed before encoded and encrypted AIDS or HIV surveillance data are transmitted to CDC.

The evaluations in Maryland an Texas indicated that the use of UIs limits the performance of an HIV surveillance system and complicates efforts to collect risk-behavior information. Both systems demonstrated timely reporting. Although data from both states indicated increases in reporting of the SSN data element during the evaluation period, overall 22% of reports in Maryland and 34% in Texas were missing the SSN element, which contributed to a high rate of incomplete case reporting. The follow-back investigation in Texas suggests that SSNs are not readily available in client or medical records but, in the controlled environment of the Maryland HIV C&T system, counselors were able to collect SSNs for most clients. The completeness of reporting also may be affected by the ability of providers and laboratories to use UIs as part of routine HIV-testing practices. For example, one large laboratory providing HIV-testing services in Maryland did not report HIV infections during the evaluation period. The difficulty in collecting HIV data when persons are tested out of state also may affect the completeness of reporting and the ability to eliminate duplicate reports. Maryland is continuing to evaluate its UI surveillance system, and Texas is exploring

alternative HIV surveillance systems with input from community groups.

Effective HIV surveillance systems must include HIV risk information; however, this information often is not available at the time of the initial UI case report, and follow-up with health-care providers is necessary. To supply follow-up information, health-care providers must use lists or other mechanisms to link the UI to patient identifiers. The UI approach complicates efforts to collect this information and increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality.

CDC has recommended that all states and territories conduct HIV case surveillance as an extension of their AIDS surveillance systems (1). In addition, CDC is developing technical guidance to enhance security practices, standardize confidentiality laws and regulations, and promote uniform standards for HIV case surveillance systems. These guidelines will assist states and territories in implementing HIV case surveillance using data-collection and data-storage methods that provide high quality HIV surveillance data while assuring the confidentiality of surveillance information.

#### References

- CDC. Update: trends in AIDS incidence, 1996. MMWR 1997;46:861-7.
- Carpenter CC, Fischl MA, Hammer SM, et al. Antiretroviral therapy for HIV infection in 1997: updated recommendations of the International AIDS Society-USA panel. JAMA 1997;277:1962-9.
- Council of State and Territorial Epidemiologists. CSTE: position statement ID-4. National HIV surveillance: addition to the National Public Health Surveillance System. Atlanta, Georgia: Council of State and Territorial Epidemiologists, 1997.
- Klaucke DN. Evaluating public health surveillance. In: Teutsch SM, Churchill RE, eds. Principals and practices of public health surveillance. New York, New York: Oxford University Press, 1994:158-74.
- Rosenblum L, Buehler JW, Morgan ME, et al. The completeness of AIDS case reporting, 1988: a multisite collaborative surveillance project. Am J Public Health 1992;82:1495-9.
- 6. CDC. HIV/AIDS surveillance report, Atlanta, Georgia: US Department of Health and Human Services, Public Health Service, 1997. (Vol 8, no. 1).
- Meyer PA, Jones JL, Garrison CZ. Completeness of reporting of diagnosed HIV-infected hospital inpatients. J AIDS 1994;7:1067-73.
- Gostin LO, Lazzarini Z, Neslund VS, Osterholm MT. The public health information infrastructure: a national review of the law on health information privacy. JAMA 1996;275:1921-7.

#### Excerpt from: The Maryland Lesson: Conducting Effective HIV Surveillance with Unique Identifiers

(New York: American Civil Liberties Union, December 1997. At www.aclu.org/issues/aids/mdnamereport.html)

Based on the evaluation of its unique identifier (UI) system for HIV reporting, Texas is seeking to implement name-based HIV reporting. However, Maryland has been more satisfied with UI reporting. This article excerpts an American Civil Liberties Union (ACLU) document supportive of UI reporting for HIV. The full text of this document and the HIV Surveillance and Reporting Policy Statement of the San Francisco AIDS Foundation (www.sfaf.org/policy/survfull.html.), also supportive of UIs, can be found on the World Wide Web.

#### Conversation with Dr. Liza Solomon, Director, Maryland AIDS Administration

**ACLU:** What should we look at to determine whether an HIV surveillance system like Unique Identifiers or names-based reporting is working?

**L.S.:** In order to assess whether a disease surveillance system is working, one must first clarify what are reasonable expectations for the system and what information is needed to accomplish the important public health goals of surveillance. If one looks to a surveillance system to give basic epidemiological information on populations that are affected and the risk practices involved, then some slight over or under-counting will not have a significant impact on the data. For example, it may only be important for epidemiological purposes to know that young heterosexual women are increasingly becoming infected with HIV. Knowing that there are 200 HIV positive women as compared to 220 will not impact service or prevention planning.

**ACLU:** What level of statistical precision is necessary in order to accomplish the public health goals we have for HIV surveillance?

**L.S.:** This question again relates to the goal of the surveillance activities. In order to plan services, prevention activities, and target programs, it is important to have a good, although not exact, idea of

\*Recommendations on HIV infection reporting. Austin: Texas Department of Health, January 1998. At http://www.tdh.state.tx.us/hivstd/stats.htm.

the number of individuals involved. Public health programs are usually targeted at populations and affected communities. Knowing each person's identity is not necessary to accomplish these goals.

**ACLU:** Would a surveillance system that included names be more helpful in insuring that individuals who need medical treatment have access to health care?

**L.S.:** Surveillance systems are not the most effective vehicle for insuring that individuals receive health care. Referring individuals into care and insuring that they have access to care is a critical public health objective. Disease registries, such as cancer registries or AIDS registries, have rarely been the means to identify individuals for referrals into care. Estimates from the Centers for Disease Control suggest that there is a significant lapse in time before an individual with AIDS is reported to the state registry. CDC estimates that 50% of people with AIDS are reported within 3 months of diagnosis while 20% are not reported to AIDS registries for more than one year. (CDC HIV/AIDS Surveillance Report, Vol. 8, 1997). Similar delays can be expected in any HIV case reporting system. Guaranteeing care and insuring that there are needed linkages to care should occur at the point of contact with the patient - at the testing site or clinician's office.

**ACLU:** Has Maryland been able to use its UI system to get accurate data for purposes of funding?

**L.S.:** Maryland has used data from its UI system to help inform decisions concerning allocation of resources and to provide information used in funding jurisdictions.

**ACLU:** Do you believe that it is possible to monitor recent trends in HIV infection in Maryland using Unique Identifiers?

**L.S.:** UI information is helpful in providing a picture of early infection and can provide information on new groups that may be affected by HIV. In a comparison of demographic information obtained from the UI registry and the AIDS registry in Maryland, we have seen that individuals with HIV are younger and more likely to be female than individuals in the AIDS registry. Using the UI and AIDS registries we have found that there is little difference by race among those with HIV and AIDS in Maryland.

**ACLU:** Has Maryland had difficulty providing services for people with HIV and AIDS because the state does not have a names-based surveillance system?

**L.S.:** Maryland has a comprehensive system of service delivery to insure that individuals needing services have access to them. In addition, Maryland has an AIDS Drug Assistance Program (ADAP) which provides medications to individuals with HIV and AIDS who have medical needs but inadequate resources to obtain medications. Maryland's ADAP provides unlimited access to all protease inhibitors and antivirals for individuals in the program. There are no waiting lists and no clinical restrictions other than a diagnosis of HIV.

**ACLU:** Would name reporting allow for more effective partner notification?

**L.S.:** Partner notification is an important component of Maryland's HIV prevention program. The contact point for insuring that partner notification is implemented is at the time that a person learns his/her HIV status. As part of Maryland's counseling procedure, when individuals receive HIV positive test results counselors inform them about the importance of partner notification and assist individuals in notifying. This process exists regardless of the surveillance system or the venue of the test, including anonymous test sites.

**ACLU:** Do we need name reporting in order to track down those individuals who are tested for HIV and do not return for their test results?

**L.S.:** It is critically important that individuals, both HIV positive and negative, learn their test results. In confidential HIV testing facilities, the patient name is known to the health care provider who orders the test. Follow-up with that patient can take place even though the State does not have a State-sponsored names-based registry of HIV. In anonymous testing facilities, the patient's name is not known to the provider. However, research shows that individuals who are tested anonymously are more likely to retrieve their test results than individuals who provide their name at the time of testing.

**ACLU:** Doesn't Maryland's requirement that providers maintain a log of those who are tested mean that the possibilities for confidentiality breaches are even greater?

**L.S.:** In Maryland, providers are required to maintain some means for surveillance staff to backtrack to obtain additional information. Providers don't necessarily keep logs. Some keep computer databases. And logs and computer databases don't need to include names. They can instead include medical record numbers or other non-name identifying information. Also, we're worried

about the perception of the person being tested and whether they will be deterred from testing. In our experience, individuals most at risk for HIV trust their doctors more than they trust government agencies. They are thus less likely to be deterred from being tested by provider logs or their equivalent.

**ACLU:** Why do you think Texas has a negative evaluation of its UI program, given the success of Maryland's program?

**L.S.:** Although Texas and Maryland have both used the same 12 digit UI number, the two states have differences in their programs. In Texas, both physicians and labs have the responsibility to report. This may have created some difficulty with the volume of reports. Also, Texas' system does not require that physicians keep a log or equivalent. Thus when questions arose there was no way to return to the physicians and get additional data. Ultimately, any new surveillance system requires considerable work with the physician community to insure that it is well-implemented. It appears that additional education efforts with labs and physicians would be helpful.

**ACLU:** Has Maryland received any money from the CDC to develop or implement its UI program? Has the state requested funds?

**L.S.:** Maryland has not received funds from the Centers for Disease Control to implement its HIV surveillance system. Maryland requested funds to support this program in our 1995, 1996 and 1997 surveillance cooperative agreement. All requests were denied. Maryland and Texas did receive funds from the CDC to evaluate the UI program.

**ACLU:** Do you think UI systems are more expensive than names-based surveillance systems?

**L.S.:** Maryland has implemented its UI system without additional funds. However, any expanded surveillance system, names-based or UI-based, does require additional resources. Although we have implemented our system without additional funds, we estimate that it would cost the State of Maryland \$100,000 to more fully implement the UI surveillance system and have it reach the level of accuracy that is realized by our AIDS surveillance system.

**ACLU:** Does Maryland plan any improvements in its UI program?

**L.S.:** We are considering two revisions to our UI system that we believe will give us additional data and

reduce errors. First, we are considering having the provider ascribe risk category and include this as part of the UI number. This would allow us to have complete risk categories for all individuals in our UI data base without needing to call the physician. In addition, we are considering changing the layout of our number. Currently the race/ethnicity categories (a 1 to 5 classification) is right next to the gender category (1,2 category). We believe this has caused transcription errors which may be reduced by changing to an alphanumeric code. We are also expanding our education and training for clinicians to help them comply with the law.

**ACLU:** Why has Maryland resisted conducting HIV surveillance through name reporting?

**L.S.:** Maryland adopted HIV surveillance by Unique Identifier after full discussion and debate within our General Assembly and our community. Bills promoting names reporting were introduced and defeated in the 1992 and 1994 General Assembly sessions. After a full discussion of these issues, legislation was passed which authorized the creation of the Unique Identifier system. This legislation has enjoyed considerable support from the HIV community. The AIDS Administration is committed to working in partnership with affected communities in all our programs.

**ACLU:** Does Maryland intend to continue using UI's, or to switch to names-based reporting?

**L.S.:** Maryland is continuing to refine and improve upon our HIV surveillance system. We have no plans to change to a names-based system.

#### Abstracts and Selected Slides from Three APHA Annual Meeting Presentations Concerning HIV Reporting

Richard Sun, M.D., M.P.H.

The November 1997 annual meeting of the American Public Health Association in Indianapolis, Indiana included a special session on "Monitoring the HIV Epidemic: Policy, Evaluation, and Future Directions." During the session, researchers presented six papers based on studies performed or

funded by the Centers for Disease Control and Prevention.

This article reprints the abstracts of three presentations given during the session and provides copies of selected slides projected during each presentation. The figures and tables here were selected from printouts of each presenter's slides that were provided to each state's AIDS surveillance coordinator in December 1997; the tables were retyped for greater legibility. For a complete copy of the three printouts of slides, please send a letter to me at the following address:

HIV/AIDS Epidemiology Branch California Department of Health Services P. O. Box 942732 Sacramento, California 94234-7320

#### IMPACT OF HIV NAME-REPORTING LAWS ON TESTING IN PUBLICLY FUNDED HIV COUNSELING AND TESTING SITES

Nakashima AK, Horsley RM, Sweeney PA, Weber JT, Fleming PL.

**Background**: The reporting by name of HIV cases to health departments has been controversial because of concerns that some persons may delay or avoid HIV testing. We examined the number of HIV tests performed and the characteristics of persons tested in publicly funded HIV counseling and testing (CT) sites before and after HIV name-reporting laws were implemented.

**Methods**: HIV CT data for six states (LA, MI, NE, NJ, TN, NV) were analyzed for trends in testing before and after HIV name reporting was introduced. In two states (LA, NE) where test type was available for the relevant period, anonymous versus confidential tests were also examined.

**Results**: The overall number of tests remained stable or increased in the year after HIV name reporting was introduced. However, increases in testing were greater for women than for men, and in LA, testing of men declined by 10%. White men who have sex with men (MSM) accounted for most of the decline in testing of men in LA. Testing among injecting drug users (IDUs) and heterosexual partners of persons at

risk for HIV remained stable or increased. In LA and NE, > 60% of tests requested by MSM were anonymous before and after HIV name reporting.

Conclusions: The impact of HIV name reporting laws on number of HIV tests performed in publicly funded HIV CT sites in these states was not significant. However, certain high risk groups (e.g., MSM) may be more likely to avoid testing or to use the anonymous test option. Therefore, states considering implementation of HIV name-reporting laws should address the concerns of these groups including confidentiality, anti-discrimination legislation and policies, availability of anonymous testing, and potential benefits (e.g., access to therapy/services, resource allocation).

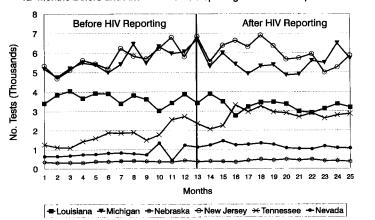
Number of HIV Tests Among White MSM by Type of Test the Year Before and the Year After HIV Name Reporting Was Implemented

| No. Anonymous HIV Tests |        |            |         |  |  |  |  |
|-------------------------|--------|------------|---------|--|--|--|--|
| State                   | Before | After      | %Change |  |  |  |  |
| Louisiana               | 448    | 348        | -22.3   |  |  |  |  |
| Nebraska                | 271    | <b>385</b> | 42.1    |  |  |  |  |

| No. <u>Confidential</u> HIV Tests |     |     |       |   |  |  |  |  |
|-----------------------------------|-----|-----|-------|---|--|--|--|--|
| State Before After %Change        |     |     |       |   |  |  |  |  |
| Louisiana                         | 160 | 174 | 8.8   | _ |  |  |  |  |
| Nebraska                          | 153 | 127 | -17.0 |   |  |  |  |  |

Source: Abstracts of the 125th Annual Meeting of the American Public Health Association, Indianapolis, 1997 November 9-13. Sossion 3108 n. 325

Number of HIV Tests Performed in Publicly-Funded HIV Counseling and Testing Sites
12 Months Before and After HIV Name Reporting Laws Were Implemented\*



\*Name Reporting Began: LA (Feb '93), MI (Apr '92), NE (Sep '95), NJ (Jan '92), TN (Jan '92), NV (Feb '92)

#### Number of HIV Tests Among <u>MSM</u> the Year Before and the Year After HIV Name Reporting Was Implemented

| No. HIV | / Tests                               |                                       |
|---------|---------------------------------------|---------------------------------------|
| Before  | After                                 | %Change                               |
| 1,332   | 1,274                                 | -4.3                                  |
| 3,905   | 4,113                                 | 5.3                                   |
| 480     | 574                                   | 19.6                                  |
| 744     | 837                                   | 8.5                                   |
| 3,556   | 3,872                                 | 8.9                                   |
| 2,734   | 2,622                                 | -4.1                                  |
|         | 1,332<br>3,905<br>480<br>744<br>3,556 | 1,332 1,274<br>3,905 4,113<br>480 574 |

#### Limitations

- CTS data collected to monitor service provision; not as high quality as data from a rigorously designed study
- CTS data are collected on tests rather than individuals
- Changes in policies, funding, or staffing may affect number of tests performed in CTS sites
- Other events, e.g., high profile media events, may also affect number of tests performed

#### **Conclusions**

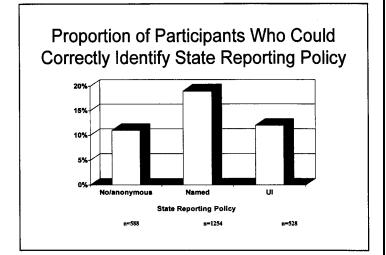
- No large declines in number of HIV tests performed in CTS sites after HIV name reporting was implemented
- No large declines in number of positive HIV tests; declines in three areas were within the expected range
- These results support interview studies showing HIV name reporting policies do not deter persons from being tested
- Availability of anonymous testing may be important for some high risk groups, e.g., MSM and injecting drug users

### NAMED HIV REPORTING: HIV TESTING SURVEY (HITS)

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The objective of the HITS survey is to assess knowledge of HIV reporting policies and perceived influence of the reporting policies on HIV testing decisions in persons at risk for HIV exposure. The study design allows comparisons of these factors in states with different HIV reporting policies. Interviews have been conducted in 9 states, 2 without HIV reporting (Oregon and New Mexico), two with unique identifier reporting (Maryland and Texas), and five with named reporting (Arizona, Colorado, Missouri, Mississippi, and North Carolina). Three at-risk populations have been interviewed: sexually active men who have sex with men (recruited at gay bars), heterosexuals with a suspected sexually transmitted disease (recruited at STD clinics), and injection drug users (recruited through street outreach). Target enrollments are 100 persons recruited from each of the three populations in each state (2700 total). In preliminary analyses of 2387 participants, 84% said they would be likely to get an HIV test in the next year if they could get an anonymous test, compared to 62% if the only option was testing with named reporting (p < 0.001). Overall, 78% of participants had been HIV tested. Of those who had not been tested, 18% reported that concern about named HIV reporting was a reason they had not been tested; this proportion was similar in states with and states without named reporting. Knowledge of reporting policies was low. Most persons in every state said they did not know the reporting policy; 31% in states with named HIV reporting knew there was named reporting, while 19% in Oregon and New Mexico thought there was named reporting. Additional analyses of knowledge of reporting policies in relation to sociodemographic characteristics and past HIV testing, and HIV testing history in relation to actual and perceived HIV reporting policies will be presented.

Source: Abstracts of the 125th Annual Meeting of the American Public Health Association, Indianapolis, 1997 November 9-13. Session 3108, p. 325.



| December No.                                       | t I IIV / Taatin a |             |  |  |  |  |  |
|--|--------------------|-------------|--|--|--|--|--|
| Reasons for Not HIV Testing Among Those Not Tested |                    |             |  |  |  |  |  |
| % Gave As % Gave As                                |                    |             |  |  |  |  |  |
| Reason   | Reason             | Main Reason |  |  |  |  |  |
| Afraid to find out                                 | 48                 | 28          |  |  |  |  |  |
| 2. Unlikely to have been exposed                   | 43                 | 20          |  |  |  |  |  |
| 3. Thought HIV negative                            | 48                 | 15          |  |  |  |  |  |
| 4. Didn't want to think about it                   | 48                 | 9           |  |  |  |  |  |
| 5. Little could do if positive                     | 32                 | 6           |  |  |  |  |  |
| 6. Didn't have time                                | 18                 | 5           |  |  |  |  |  |
| 7. Unsure where to go                              | 22                 | 4           |  |  |  |  |  |
| 8. Worried name would                              |                    | _           |  |  |  |  |  |
| be reported to gov't                               | 19                 | 2           |  |  |  |  |  |
| 9. People might think you have                     | 47                 | 0           |  |  |  |  |  |
| AIDS   | 17                 | 2           |  |  |  |  |  |
| 10. Test costs too much                            | 8                  | 2           |  |  |  |  |  |

#### Limitations

- Many recruitment venues have had outreach
  - May overestimate knowledge
  - May underestimate concern about reporting
- Response bias
- Generalizability uncertain
  - e.g., MSM at bars may be different from MSM who don't go to bars  $\,$
- Slated intent to test may not match actual behavior

#### Conclusions

- Knowledge of HIV reporting policies is low
- Concern about named reporting sometimes delays testing, but is rarely the main reason for not testing
- Eliminating anonymous testing might decrease testing rates

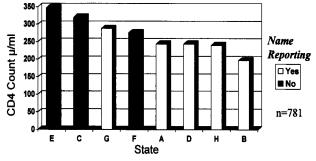
## THE AIDS PATIENT SURVEY: ASSESSING THE EFFECT OF STATE HIV TESTING AND REPORTING POLICIES ON THE HEALTH CARE SEEKING BEHAVIOR OF PERSONS WITH AIDS

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The AIDS Patient Survey (APS), a population based survey of persons reported with AIDS was conducted from 5/95-2/97 in eight states (AZ, CO, MS, MO, NC, NM, OR, TX) collaboratively by the eight state health departments, UCSF and CDC. The primary objective of this survey was to determine whether state HIV testing and reporting policies influenced the timing (in terms of disease progression) of when persons with AIDS obtained medical care. Persons reported with AIDS who were adults (> = 13 years), residents of the state, and whose report was within 12 months of diagnosis were eligible for study participation. A random sample of persons reported with AIDS, weighted by risk exposure category, was drawn in four higher morbidity states (CO, MO, NC, TX). In lower morbidity states (AZ, MS, NM, OR), all eligible persons were included in the sample. Following locally approved procedures to ensure confidentiality, eligible cases were recruited for study participation. Using trained interviewers and English and Spanish language questionnaires, subjects were asked about demographic and socioeconomic indicators, HIV testing history (including type of test sought and reasons for seeking or delaying testing), risk behaviors for HIV, whether or not and why they sought HIV-related health care services, and what services they sought. As of 2/97, > 1900 interviews had been completed across the eight states, and data entry is nearly complete. These data will be useful in national and state efforts to ensure surveillance efforts that promote early access to health care for all persons with AIDS.

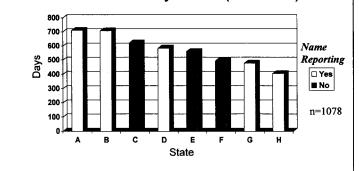
Source: Abstracts of the 125th Annual Meeting of the American Public Health Association, Indianapolis, 1997 November 9-13. Session 3108, p. 325.

## Adjusted\* Mean Self-Reported First CD4 Count by State (1990-97)



\* adjusted for age, sex, race/ethnicity, education, income, health insurance, risk behavior, confidential/anonymous testing, regular medical care prior to testing

## Adjusted Intervals in Time from HIV + Test to AIDS by State (1990-97)



#### Limitations

- Type of testing and state reporting policy not randomized
- Inaccuracy of self-reports
- State differences not captured by measured variables
- Comparisons of state-level variables have only 8 data points

#### Conclusions

- Reporting concerns rarely the main reason for delaying entry into care
- Mean CD4 count lower in named reporting states
  - May reflect differences in outreach and accessibility of care as well as effect of reporting
- No difference in time from HIV diagnosis to AIDS diagnosis based on reporting policies
- Health department contact to about medical care
  - Variable proportions contacted, some found it useful
  - Not associated with more rapid access to care

Table 1. AIDS cases by age group, exposure category, and gender reported January 1, 1996 through December 31, 1996 and January 1, 1997 through December 31, 1997; and cumulative totals by age group through December 31, 1997 in California.

|  | Male                               |                                    | Female                             | <u> </u>                           |                                    | Totals                             |                                |
|--|------------------------------------|------------------------------------|------------------------------------|------------------------------------|------------------------------------|------------------------------------|--------------------------------|
| Adult/adolescent<br>Exposure Category              | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Cumulative<br>Total<br>No. (%) |
| Homosexual/bisexual                                | 6,071 (74)                         | 4,190 (69)                         | ()                                 | ()                                 | 6,071 (66)                         | 4,190 (62)                         | 75,260 (72)                    |
| IDU (heterosexual)                                 | 849 (10)                           | 658 (11)                           | 324 (36)                           | 227 (32)                           | 1,173 (13)                         | 885 (13)                           | 10,141 (10)                    |
| Homosexual/bisexual<br>IDU                         | 677 (8)                            | 405 (7)                            | ()                                 | ()                                 | 677 (7)                            | 405 (6)                            | 8,825 (8)                      |
| Lesbian/bisexual IDU                               | ()                                 | ()                                 | 12 (1)                             | 8 (1)                              | 12 ()                              | 8 ()                               | 115 ()                         |
| Coagulation Disorders                              | 34 ()                              | 21 ()                              | ()                                 | 1 ()                               | 34 ()                              | 22 ()                              | 523 (1)                        |
| Heterosexual                                       | 162 (2)                            | 140 (2)                            | 417 (46)                           | 318 (45)                           | 579 (6)                            | 458 (7)                            | 4,052 (4)                      |
| Blood transfusion                                  | 55 (1)                             | 32 (1)                             | 31 (3)                             | 22 (3)                             | 86 (1)                             | 54 (1)                             | 1,534 (1)                      |
| Other/undetermined                                 | 407 (5)                            | 623 (10)                           | 115 (13)                           | 137 (19)                           | 522 (6)                            | 760 (11)                           | 3,635 (3)                      |
| Subtotal   | 8,255 (100)                        | 6,069 (100)                        | 899 (100)                          | 713 (100)                          | 9,154 (100)                        | 6,782 (100)                        | 104,085 (100)                  |
| Pediatric (< 13 years<br>old)<br>Exposure Category | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Cumulative<br>Total<br>No. (%) |
| Coagulation Disorders                              | 1 (4)                              | ()                                 | ()                                 | ()                                 | 1 (2)                              | ()                                 | 29 (5)                         |
| Blood transfusion                                  | ()                                 | ()                                 | ()                                 | 1 (14)                             | ()                                 | 1 (6)                              | 111 (20)                       |
| Mother at risk:<br>IDU                             | 6 (24)                             | 4 (36)                             | 2 (11)                             | 1 (14)                             | 8 (18)                             | 5 (28)                             | 146 (26)                       |
| Sex with IDU                                       | 3 (12)                             | ()                                 | 2 (11)                             | 1 (14)                             | 5 (11)                             | 1 (6)                              | 76 (14)                        |
| Sex w/bisexual male                                | 1 (4)                              | ()                                 | 2 (11)                             | ()                                 | 3 (7)                              | ()                                 | 26 (5)                         |
| Sex w/HIV infected                                 | 3 (12)                             | 1 (9)                              | 6 (32)                             | 3 (43)                             | 9 (20)                             | 4 (22)                             | 64 (12)                        |
| Blood transfusion                                  | 1 (4)                              | 2 (18)                             | 3 (16)                             | ()                                 | 4 (9)                              | 2 (11)                             | 22 (4)                         |
| HIV infected                                       | 10 (40)                            | 3 (27)                             | 4 (21)                             | 1 (14)                             | 14 (32)                            | 4 (22)                             | 72 (13)                        |
| Other/undetermined                                 | ()                                 | 1 (9)                              | ()                                 | ()                                 | ()                                 | 1 (6)                              | 7 (1)                          |
| Subtotal   | 25 (100)                           | 11 (100)                           | 19 (100)                           | 7 (100)                            | 44 (100)                           | 18 (100)                           | 553 (100)                      |
| TOTAL  | 8,280                              | 6,080                              | 918                                | 720                                | 9,198                              | 6,800                              | 104,638                        |

Table 2. AIDS cases by age group, exposure category, and race/ethnicity reported through December 31, 1997 in California.

| Adult/adolescent<br>Exposure Category              | White<br>No. (%) | Black<br>No. (%) | Hispanic<br>No. (%) | Asian/<br>Pacific Is.<br>No. (%) | Native<br>American<br>No. (%) | Not<br>Specified<br>No. (%) | TOTAL<br>No. (%) |
|--|------------------|------------------|---------------------|----------------------------------|-------------------------------|-----------------------------|------------------|
| Homosexual/bisexual                                | 51,792 (80)      | 8,647 (51)       | 12,891 (67)         | 1,556 (75)                       | 254 (58)                      | 120 (75)                    | 75,260 (72)      |
| IDU (heterosexual)                                 | 3,804 (6)        | 4,136 (24)       | 2,031 (11)          | 88 (4)                           | 66 (15)                       | 16 (10)                     | 10,141 (10)      |
| Homosexual/bisexual IDU                            | 5,701 (9)        | 1,643 (10)       | 1,324 (7)           | 72 (3)                           | 80 (18)                       | 5 (3)                       | 8,825 (8)        |
| Lesbian/bisexual IDU                               | 49 ()            | 40 ()            | 21 ()               | 1 ()                             | 4 (1)                         | ()                          | 115 ()           |
| Coagulation Disorders                              | 354 (1)          | 41 ()            | 101 (1)             | 22 (1)                           | 1 ()                          | 4 (3)                       | 523 (1)          |
| Heterosexual                                       | 1,479 (2)        | 1,270 (7)        | 1,152 (6)           | 130 (6)                          | 18 (4)                        | 3 (2)                       | 4,052 (4)        |
| Blood transfusion                                  | 894 (1)          | 172 (1)          | 353 (2)             | 108 (5)                          | 3 (1)                         | 4 (3)                       | 1,534 (1)        |
| Other/undetermined                                 | 1,050 (2)        | 1,021 (6)        | 1,441 (7)           | 102 (5)                          | 13 (3)                        | 8 (5)                       | 3,635 (3)        |
| Subtotal   | 65,123 (100)     | 16,970 (100)     | 19,314 (100)        | 2,079 (100)                      | 439 (100)                     | 160 (100)                   | 104,085 (100)    |
| Pediatric (< 13 years<br>old)<br>Exposure Category | White<br>No. (%) | Black<br>No. (%) | Hispanic<br>No. (%) | Asian/<br>Pacific Is.<br>No. (%) | Native<br>American<br>No. (%) | Not<br>Specified<br>No. (%) | TOTAL<br>No. (%) |
| Coagulation Disorders                              | 15 (9)           | 1 (1)            | 11 (5)              | 2 (13)                           | ()                            | ()                          | 29 (5)           |
| Blood transfusion                                  | 41 (26)          | 23 (14)          | 40 (20)             | 7 (47)                           | ()                            | ()                          | 111 (20)         |
| Mother at risk:IDU                                 | 50 (31)          | 68 (40)          | 24 (12)             | ()                               | 4 (80)                        | ()                          | 146 (26)         |
| sex with IDU                                       | 17 (11)          | 20 (12)          | 37 (18)             | 1 (7)                            | 1 (20)                        | ()                          | 76 (14)          |
| sex with bisexual male                             | 8 (5)            | 4 (2)            | 13 (6)              | 1 (7)                            | ()                            | ()                          | 26 (5)           |
| sex w/HIV infected                                 | 9 (6)            | 12 (7)           | 39 (19)             | 3 (20)                           | ()                            | 1 (100)                     | 64 (12)          |
| blood transfusion                                  | 8 (5)            | 3 (2)            | 11 (5)              | ()                               | ()                            | ()                          | 22 (4)           |
| HIV infected                                       | 11 (7)           | 37 (22)          | 23 (11)             | 1 (7)                            | ()                            | ()                          | 72 (13)          |
| Other/undetermined                                 | 1 (1)            | 2 (1)            | 4 (2)               | ()                               | ()                            | ()                          | 7 (1)            |
| Subtotal   | 160 (100)        | 170 (100)        | 202 (100)           | 15 (100)                         | 5 (100)                       | 1 (100)                     | 553 (100)        |
| TOTAL  | 65,283           | 17,140           | 19,516              | 2,094                            | 444                           | 161                         | 104,638          |

Table 3. Adult/adolescent AIDS cases by gender, exposure category, and race/ethnicity, reported through December 31, 1997 in California.

| Male<br>Exposure Category  | White<br>No. (%)  | Black<br>No. (%)                                    | Hispanic<br>No. (%)                                 | Asian/<br>Pacific Is.<br>No. (%)                           | Native<br>American<br>No. (%)                           | Not<br>Specified<br>No. (%)               | TOTAL<br>No. (%)   |
|--|---|---|---|--|---|---|--|
| Homosexual/bisexual  | 51,792 (83)   | 8,647 (59)  | 12,891 (73)   | 1,556 (83)   | 254 (64)  | 120 (78)                                  | 75,260 (77)  |
| IDU (heterosexual)   | 2,828 (5)   | 2,980 (20)  | 1,681 (9)   | 58 (3)   | 43 (11)   | 11 (7)                                    | 7,601 (8)  |
| Homosexual/bisexual<br>IDU   | 5,701 (9)   | 1,643 (11)  | 1,324 (7)   | 72 (4)   | 80 (20)   | 5 (3)                                     | 8,825 (9)  |
| Coagulation Disorders  | 340 (1)   | 39 ()   | 99 (1)  | 22 (1)   | 1 ()  | 4 (3)                                     | 505 (1)  |
| Heterosexual   | 401 (1)   | 384 (3)   | 354 (2)   | 27 (1)   | 5 (1)   | 3 (2)                                     | 1,174 (1)  |
| Blood transfusion  | 575 (1)   | 83 (1)  | 167 (1)   | 61 (3)   | 2 (1)   | 3 (2)                                     | 891 (1)  |
| Other/undetermined   | 880 (1)   | 777 (5)   | 1,258 (7)   | 83 (4)   | 9 (2)   | 8 (5)                                     | 3,015 (3)  |
| Subtotal   | 62,517 (100)  | 14,553 (100)  | 17,774 (100)  | 1,879 (100)  | 394 (100)   | 154 (100)                                 | 97,271 (100)   |
|  |   |   |   |  |   |   |  |
| Female<br>Exposure Category  | White<br>No. (%)  | Black<br>No. (%)                                    | Hispanic<br>No. (%)                                 | Asian/<br>Pacific Is.<br>No. (%)                           | Native<br>American<br>No. (%)                           | Not<br>Specified<br>No. (%)               | TOTAL<br>No. (%)   |
|  |   |   |   | Pacific Is.  | American  | Specified                                 |  |
| <b>Exposure Category</b>   | No. (%)   | No. (%)   | No. (%)   | Pacific Is.<br>No. (%)                                     | American<br>No. (%)                                     | Specified<br>No. (%)                      | No. (%)  |
| Exposure Category IDU  | <b>No. (%)</b> 976 (37)                                 | <b>No. (%)</b> 1,156 (48)                           | <b>No. (%)</b> 350 (23)                             | Pacific Is. No. (%) 30 (15)                                | American<br>No. (%)<br>23 (51)                          | <b>Specified No. (%)</b> 5 (83)           | No. (%) 2,540 (37)                                       |
| IDU Lesbian/bisexual IDU   | No. (%) 976 (37) 49 (2)                                 | No. (%) 1,156 (48) 40 (2)                           | No. (%) 350 (23) 21 (1)                             | Pacific Is. No. (%)  30 (15)  1 (1)                        | American<br>No. (%)<br>23 (51)<br>4 (9)                 | <b>Specified No. (%)</b> 5 (83)  ()       | No. (%) 2,540 (37) 115 (2)                               |
| IDU Lesbian/bisexual IDU Coagulation Disorders   | No. (%) 976 (37) 49 (2) 14 (1)                          | No. (%)  1,156 (48)  40 (2)  2 ()                   | No. (%) 350 (23) 21 (1) 2 ()                        | Pacific Is. No. (%)  30 (15)  1 (1)  ()                    | American<br>No. (%)<br>23 (51)<br>4 (9)<br>()           | Specified No. (%)  5 (83)  ()  ()         | No. (%) 2,540 (37) 115 (2) 18 ()                         |
| IDU Lesbian/bisexual IDU Coagulation Disorders Heterosexual  | No. (%)  976 (37)  49 (2)  14 (1)  1,078 (41)           | No. (%)  1,156 (48)  40 (2)  2 ()  886 (37)         | No. (%)  350 (23)  21 (1)  2 ()  798 (52)           | Pacific Is. No. (%)  30 (15)  1 (1)  ()  103 (52)          | American<br>No. (%)  23 (51)  4 (9)  ()  13 (29)        | Specified No. (%)  5 (83)  ()  ()         | No. (%)  2,540 (37)  115 (2)  18 ()  2,878 (42)          |
| Exposure Category  IDU  Lesbian/bisexual IDU  Coagulation Disorders  Heterosexual  Blood transfusion | No. (%)  976 (37)  49 (2)  14 (1)  1,078 (41)  319 (12) | No. (%)  1,156 (48)  40 (2)  2 ()  886 (37)  89 (4) | No. (%)  350 (23)  21 (1)  2 ()  798 (52)  186 (12) | Pacific Is. No. (%)  30 (15)  1 (1)  ()  103 (52)  47 (24) | American<br>No. (%)  23 (51)  4 (9)  ()  13 (29)  1 (2) | Specified No. (%)  5 (83)  ()  ()  1 (17) | No. (%)  2,540 (37)  115 (2)  18 ()  2,878 (42)  643 (9) |

#### Errata

The July 1997 issue of the *California HIV/AIDS Update* contains two incorrect column totals on Table 3, page 60. The column total for "Hispanic" should be 18,442 (instead of 1,986). The column total for "Asian/Pacific Is." should be 1,986 (instead of 20,428). We apologize for these errors.

Table 4. AIDS cases in adolescents and adults under age 25, by exposure category reported January 1, 1996 through December 31, 1996 and January 1, 1997 through December 31, 1997; and cumulative totals by age group through December 31, 1997 in California.

13-19 years old

20-24 years old

| Exposure Category       | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Cumulative<br>Total<br>No. (%) | Jan. 1996-<br>Dec. 1996<br>No. (%) | Jan. 1997-<br>Dec. 1997<br>No. (%) | Cumulative<br>Total<br>No. (%) |
|-------------------------|------------------------------------|------------------------------------|--------------------------------|------------------------------------|------------------------------------|--------------------------------|
| Homosexual/bisexual     | 8 (32)                             | 10 (31)                            | 91 (31)                        | 145 (59)                           | 117 (60)                           | 1,861 (61)                     |
| IDU (heterosexual)      | 1 (4)                              | ()                                 | 9 (3)                          | 22 (9)                             | 20 (10)                            | 292 (10)                       |
| Homosexual/bisexual IDU | ()                                 | 3 (9)                              | 13 (4)                         | 16 (6)                             | 6 (3)                              | 352 (12)                       |
| Lesbian/bisexual IDU    | ()                                 | ()                                 | ()                             | ()                                 | ()                                 | 5 ()                           |
| Coagulation Disorders   | 7 (28)                             | 2 (6)                              | 75 (26)                        | 6 (2)                              | 1 (1)                              | 63 (2)                         |
| Heterosexual            | 5 (20)                             | 2 (6)                              | 40 (14)                        | 30 (12)                            | 23 (12)                            | 266 (9)                        |
| Blood transfusion       | 3 (12)                             | 8 (25)                             | 43 (15)                        | 2 (1)                              | ()                                 | 36 (1)                         |
| Other/undetermined      | 1 (4)                              | 7 (22)                             | 20 (7)                         | 26 (11)                            | 27 (14)                            | 152 (5)                        |
| TOTAL                   | 25 (100)                           | 32 (100)                           | 291 (100)                      | 247 (100)                          | 194 (100)                          | 3,027 (100)                    |

Table 5. AIDS cases by gender, age at diagnosis, and race/ethnicity, reported through December 31, 1997 in California.

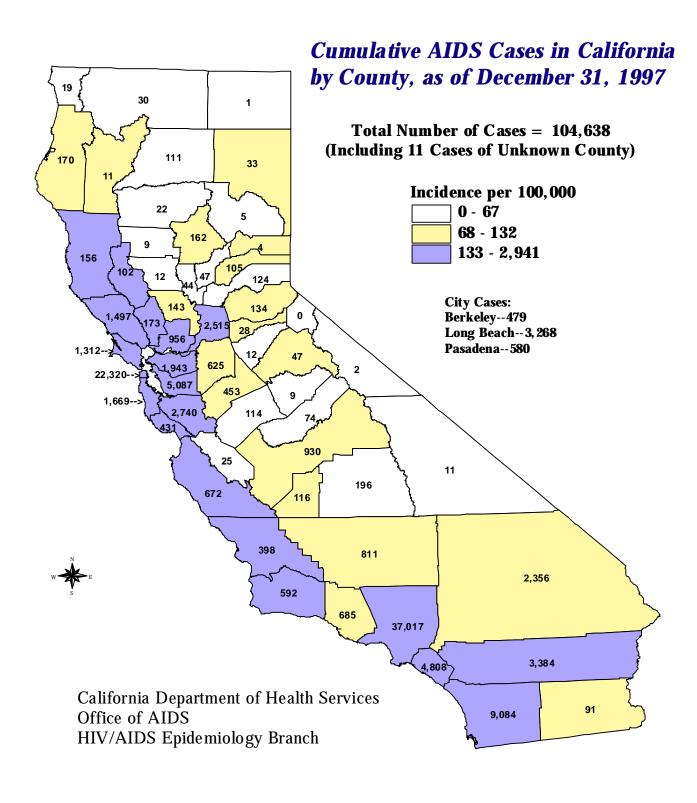
| Male<br>Age at Diagnosis<br>Years   | White<br>No. (%) | Black<br>No. (%) | Hispanic<br>No. (%) | Asian/<br>Pacific Is.<br>No. (%) | Native<br>American<br>No. (%) | Not<br>Specified<br>No. (%) | TOTAL<br>No. (%) |
|-------------------------------------|------------------|------------------|---------------------|----------------------------------|-------------------------------|-----------------------------|------------------|
| 0-4                                 | 46 ()            | 62 ()            | 70 ()               | 4 ()                             | 2 (1)                         | ()                          | 184 ()           |
| 5-12                                | 37 ()            | 28 ()            | 36 ()               | 4 ()                             | ()                            | ()                          | 105 ()           |
| 13-19                               | 73 ()            | 33 ()            | 101 (1)             | 8 ()                             | 2 (1)                         | ()                          | 217 ()           |
| 20-24                               | 1,239 (2)        | 432 (3)          | 869 (5)             | 59 (3)                           | 14 (4)                        | 5 (3)                       | 2,618 (3)        |
| 25-29                               | 6,882 (11)       | 1,913 (13)       | 3,288 (18)          | 241 (13)                         | 76 (19)                       | 22 (14)                     | 12,422 (13)      |
| 30-34                               | 13,838 (22)      | 3,351 (23)       | 4,564 (26)          | 407 (22)                         | 109 (28)                      | 32 (21)                     | 22,301 (23)      |
| 35-39                               | 14,359 (23)      | 3,353 (23)       | 3,740 (21)          | 419 (22)                         | 94 (24)                       | 36 (23)                     | 22,001 (23)      |
| 40-44                               | 11, 067 (18)     | 2,475 (17)       | 2,425 (14)          | 352 (19)                         | 51 (13)                       | 27 (18)                     | 16,397 (17)      |
| 45-49                               | 6,992 (11)       | 1,448 (10)       | 1,264 (7)           | 197 (10)                         | 24 (6)                        | 13 (8)                      | 9,938 (10)       |
| 50-54                               | 3,888 (6)        | 783 (5)          | 714 (4)             | 82 (4)                           | 10 (3)                        | 7 (5)                       | 5,484 (6)        |
| 55-59                               | 2,139 (3)        | 404 (3)          | 424 (2)             | 61 (3)                           | 9 (2)                         | 7 (5)                       | 3,044 (3)        |
| 60-64                               | 1,153 (2)        | 213 (1)          | 222 (1)             | 26 (1)                           | 3 (1)                         | 2 (1)                       | 1,619 (2)        |
| 65 or older                         | 887 (1)          | 148 (1)          | 163 (1)             | 27 (1)                           | 2 (1)                         | 3 (2)                       | 1,230 (1)        |
| Subtotal                            | 62,600 (100)     | 14,643 (100)     | 17,880 (100)        | 1,887 (100)                      | 396 (100)                     | 154 (100)                   | 97,560 (100)     |
| Female<br>Age at Diagnosis<br>Years | White<br>No. (%) | Black<br>No. (%) | Hispanic<br>No. (%) | Asian/<br>Pacific Is.<br>No. (%) | Native<br>American<br>No. (%) | Not<br>Specified<br>No. (%) | TOTAL<br>No. (%) |
| 0-4                                 | 51 (2)           | 65 (3)           | 77 (5)              | 4 (2)                            | 3 (6)                         | 1 (14)                      | 201 (3)          |
| 5-12                                | 26 (1)           | 15 (1)           | 19 (1)              | 3 (1)                            | ()                            | ()                          | 63 (1)           |
| 13-19                               | 22 (1)           | 22 (1)           | 27 (2)              | 3 (1)                            | ()                            | ()                          | 74 (1)           |
| 20-24                               | 134 (5)          | 124 (5)          | 141 (9)             | 7 (3)                            | 3 (6)                         | ()                          | 409 (6)          |
| 25-29                               | 388 (14)         | 328 (13)         | 296 (18)            | 30 (14)                          | 8 (17)                        | ()                          | 1,050 (15)       |
| 30-34                               | 566 (21)         | 498 (20)         | 320 (20)            | 27 (13)                          | 11 (23)                       | 2 (29)                      | 1,424 (20)       |
| 35-39                               | 471 (18)         | 547 (22)         | 272 (17)            | 44 (21)                          | 9 (19)                        | 1 (14)                      | 1,344 (19)       |
| 40-44                               | 369 (14)         | 415 (17)         | 190 (12)            | 23 (11)                          | 5 (10)                        | 1 (14)                      | 1,003 (14)       |
| 45-49                               | 237 (9)          | 245 (10)         | 104 (6)             | 26 (13)                          | 3 (6)                         | 1 (14)                      | 616 (9)          |
| 50-54                               | 123 (5)          | 96 (4)           | 72 (4)              | 13 (6)                           | 4 (8)                         | ()                          | 308 (4)          |
| 55-59                               | 72 (3)           | 72 (3)           | 54 (3)              | 10 (5)                           | 1 (2)                         | ()                          | 209 (3)          |
| 60-64                               | 66 (2)           | 33 (1)           | 35 (2)              | 6 (3)                            | ()                            | ()                          | 140 (2)          |
| 65 or older                         | 158 (6)          | 37 (1)           | 29 (2)              | 11 (5)                           | 1 (2)                         | 1 (14)                      | 237 (3)          |
| Subtotal                            | 2,683 (100)      | 2,497 (100)      | 1,636 (100)         | 207 (100)                        | 48 (100)                      | 7 (100)                     | 7,078 (100)      |
| TOTAL                               | 65,283           | 17,140           | 19,516              | 2,094                            | 444                           | 161                         | 104,638          |

Table 6. AIDS cases, deaths, and case-fatality rates by half-year of diagnosis through December 31, 1997 in California.

| Half-Year of  | Number   | Number    | Case          |
|---------------|----------|-----------|---------------|
| Diagnosis     | of Cases | of Deaths | Fatality Rate |
| Before 1983   | 304      | 289       | 95%           |
| 1983 Jan-June | 296      | 286       | 97%           |
| July-Dec      | 412      | 395       | 96%           |
| 1984 Jan-June | 591      | 571       | 97%           |
| July-Dec      | 816      | 783       | 96%           |
| 1985 Jan-June | 1,160    | 1,120     | 97%           |
| July-Dec      | 1,422    | 1,366     | 96%           |
| 1986 Jan-June | 1,833    | 1,770     | 97%           |
| July-Dec      | 2,231    | 2,130     | 95%           |
| 1987 Jan-June | 2,752    | 2,627     | 95%           |
| July-Dec      | 2,884    | 2,711     | 94%           |
| 1988 Jan-June | 3,254    | 3,041     | 93%           |
| July-Dec      | 3,359    | 3,071     | 91%           |
| 1989 Jan-June | 3,960    | 3,552     | 90%           |
| July-Dec      | 3,891    | 3,450     | 89%           |
| 1990 Jan-June | 4,490    | 3,856     | 86%           |
| July-Dec      | 4,434    | 3,752     | 85%           |
| 1991 Jan-June | 5,284    | 4,297     | 81%           |
| July-Dec      | 6,115    | 4,762     | 78%           |
| 1992 Jan-June | 6,521    | 4.644     | 71%           |
| July-Dec      | 6,427    | 4,236     | 66%           |
| 1993 Jan-June | 6,364    | 3,692     | 58%           |
| July-Dec      | 5,592    | 2,777     | 50%           |
| 1994 Jan-June | 5,492    | 2,267     | 41%           |
| July-Dec      | 4,771    | 1,575     | 33%           |
| 1995 Jan-June | 4,966    | 1,224     | 25%           |
| July-Dec      | 4,209    | 813       | 19%           |
| 1996 Jan-June | 3,918    | 570       | 15%           |
| July-Dec      | 2,967    | 336       | 11%           |
| 1997 Jan-June | 2,532    | 225       | 9%            |
| July-Dec      | 1,391    | 75        | 5%            |
| TOTAL         | 104,638  | 66,263    | 63%           |

Table 7. AIDS Cases and Cumulative Incidence 1981 through December 31, 1997 in California.

|              | AIDS   |        | Case<br>Fatality | Incidence<br>Per |                 | AIDS    |        | Case<br>Fatality | Incidence<br>Per |
|--------------|--------|--------|------------------|------------------|-----------------|---------|--------|------------------|------------------|
| County       | Cases  | Deaths | <b>Rate</b> (%)  | 100,000          | County          | Cases   | Deaths | <b>Rate</b> (%)  | 100,000          |
| Alameda      | 5,087  | 3,223  | 63.4%            | 365.16           | Orange          | 4,808   | 2,723  | 26.6%            | 177.24           |
| Berkeley     | 479    | 326    | 68.1%            | 456.63           | Placer          | 124     | 29     | 54.0%            | 56.76            |
| Alpine       | 1      | 1      | 1                | 1                | Plumas          | 5       | 3      | 80.09            | 22.91            |
| Amador       | 28     | 17     | %2.09            | 84.31            | Riverside       | 3,384   | 1,819  | 53.8%            | 218.11           |
| Butte        | 162    | 115    | 71.0%            | 79.48            | Sacramento      | 2,515   | 1,619  | 64.4%            | 206.82           |
| Calaveras    | 12     | 7      | 58.3%            | 27.41            | San Benito      | 25      | 10     | 40.0%            | 56.37            |
| Colusa       | 12     | 11     | 91.7%            | 62.38            | San Bernardino  | 2,356   | 1,358  | 27.6%            | 132.40           |
| Contra Costa | 1,943  | 1,262  | 65.0%            | 213.61           | San Diego       | 9,084   | 5,451  | %0.09            | 333.24           |
| Del Norte    | 19     | 10     | 52.6%            | 61.57            | San Francisco   | 22,320  | 15,294 | 88.5%            | 2,940.81         |
| El Dorado    | 134    | 98     | 64.2%            | 85.11            | San Joaquin     | 625     | 398    | 63.7%            | 111.30           |
| Fresno       | 930    | 285    | 62.9%            | 112.37           | San Luis Obispo | 398     | 184    | 46.2%            | 172.09           |
| Glenn        | 6      | 9      | %2.99            | 31.57            | San Mateo       | 1,669   | 1,050  | 62.9%            | 234.74           |
| Humboldt     | 170    | 102    | %0.09            | 129.16           | Santa Barbara   | 265     | 419    | %8.02            | 148.77           |
| Imperial     | 91     | 46     | 50.5%            | 67.93            | Santa Clara     | 2,740   | 1,656  | 60.4%            | 168.11           |
| Inyo         | 111    | 7      | 63.6%            | 56.38            | Santa Cruz      | 431     | 598    | 61.7%            | 178.87           |
| Kern         | 811    | 400    | 49.3%            | 119.32           | Shasta          | 111     | 84     | 75.7%            | 62.44            |
| Kings        | 116    | 54     | 46.6%            | 102.69           | Sierra          | 4       | 4      | 100.0%           | 119.40           |
| Lake         | 102    | 22     | 53.9%            | 166.12           | Siskiyou        | 30      | 16     | 53.3%            | 63.88            |
| Lassen       | 33     | 13     | 39.4%            | 122.88           | Solano          | 926     | 542    | 26.7%            | 230.20           |
| Los Angeles  | 37,017 | 23,815 | 64.3%            | 384.13           | Sonoma          | 1,497   | 950    | 63.5%            | 340.15           |
| Long Beach   | 3,268  | 2,062  | 63.1%            | 746.46           | Stanislaus      | 453     | 272    | %0.09            | 100.03           |
| Pasadena     | 280    | 378    | 65.2%            | 431.55           | Sutter          | 44      | 27     | 61.4%            | 55.40            |
| Madera       | 74     | 42     | 26.8%            | 65.63            | Tehama          | 22      | 11     | 20.0%            | 37.35            |
| Marin        | 1,312  | 707    | 53.9%            | 543.57           | Trinity         | 11      | ∞      | 72.7%            | 77.64            |
| Mariposa     | 6      | 3      | 33.3%            | 50.57            | Tulare          | 196     | 137    | 86.69            | 51.71            |
| Mendocino    | 156    | 107    | 89.89            | 171.92           | Tuolumne        | 47      | 30     | 63.8%            | 83.87            |
| Merced       | 114    | 70     | 61.4%            | 53.16            | Ventura         | 685     | 440    | 64.2%            | 93.00            |
| Modoc        | 1      | 1      | 100.0%           | 9.23             | Yolo            | 143     | 88     | 61.5%            | 60.06            |
| Mono         | 2      | 1      | 20.0%            | 18.48            | Yuba            | 47      | 53     | 61.7%            | 67.36            |
| Monterey     | 672    | 390    | 28.0%            | 176.62           | Unknown         | 111     | 9      | 54.5%            |                  |
| Napa         | 173    | 108    | 62.4%            | 143.50           |                 |         |        |                  |                  |
| Nevada       | 105    | 59     | 56.2%            | 109.03           | TOTAL           | 104,638 | 66,263 | 63.3%            | 311.07           |
|              |        |        |                  |                  |                 |         |        |                  | Ī                |



#### **MEETINGS/ANNOUNCEMENTS**

**March 24-27, 1998** 10th National AIDS Update Conference, Our Nation's Challenge: The Next Decade, Bill Graham Civic Auditorium, San Francisco, CA. For more information, contact Krebs Convention Management Services, 415-920-7000 (phone) or 415-920-7001 (fax) or www.nauc.org.

**April 15, 1998** 11th Annual HIV/AIDS on the Front Line Conference, the Doubletree Hotel, Costa Mesa, CA. Sponsored by the University of California, Irvine; the Irvine Pacific AIDS Education and Training Center; and the Orange County Health Care Agency. For more information, contact the Conference Information Line, 714-834-8020.

**April 28 - May 1, 1998** Statewide AIDS Surveillance Conference, the Handlery Hotel & Resort, San Diego, CA. Sponsored by the California Department of Health Services, Office of AIDS, for local health department surveillance staff. For more information, contact Joseph Poindexter, 916-327-3189 or Lori Rodriguez, 916-322-0891.

**June 5, 1998** 12th Annual AIDS Conference: The Science of HIV Medicine - The Art of Delivering Care, Mills College, Oakland CA. Sponsored by the Alta Bates Medical Center East Bay AIDS Center. For more information, contact Caroline Carey, Medical Education Conference Coordinator, 510-204-3884.

**June 28 - July 3, 1998** 12th World AIDS Conference, Geneva, Switzerland. Sponsored by the International AIDS Society. For more information, contact C/o Congrex(Sweden)AB, P. O. Box 5619, S-114 86 Stockholm, Sweden, + 46 8 612 69 00 (phone) + 46 8 612 62 92 (fax), aids98@congrex.se (email) or http://www.aids98.ch (Internet).

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